

Susan Conley, A Survivor's Perspective March 13, 2011 Welcome to Yale Cancer Center Answers with doctors Francine Foss and Lynn Wilson. I am Bruce Barber. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1888-234-4YCC. This evening, we continue our series of survivor stories with our guest host Peter Lamothe, who is a cancer survivor himself. Peter is joined by Susan Conley, a breast cancer survivor who wrote a book about her experience called *The Foremost Good Fortune*. Here is Peter Lamothe. Lamothe Let us begin at the beginning, when you decided that you were going to take an around-the-globe extended trip to Beijing. Tell us about when your husband, Tony, first floated the idea of moving to Beijing with the family and whether you jumped at it right away, gave it consideration, what happened? Conley I say in the book that when I married Tony there was a triangulation of me, Tony, and China. So, China was always in the cards for us. He was one of those old China hands who had lived in China before and when he got a chance to open an office there, I have to say we jumped at it. Lamothe And what does your husband do, or what did he do there? Conley He is a consultant who opened an office there to try to help the state owned banks begin to develop credit systems. Lamothe Terrific. Lamothe So, the four of you go there, because you have two young boys. Conley Right. Lamothe What was the adjustment like for you and your family? Conley Tony is a fluent Mandarin speaker, the boys and I spoke not a word, and what I do in the book is trace how the more language we learned, the more comfortable we got. For us the adjustment was all about language. There is a myth that people in Beijing speak English, because there really was not much on the streets for us. Lamothe When did you arrive there? Conley We got there in 2006 and we were there for almost three years. 2:16 into mp3 file <http://yalecancercenter.org/podcast/mar1311-cancer-answers-conley.mp3> Lamothe So, your husband was familiar with it and had the language down, it was a new adventure for you and for the boys, I am sure you took charge with them and got them situated, what was it like? Conley It was like landing on Mars for a while. We went from the small life in a city in Maine to one of the biggest cities in the world. I open the book by saying, "without turning my neck I can see 100 skyscrapers." It was urban, and teeming, dazzling, fascinating, and confusing. Lamothe I think we can imagine what would make it confusing, but what made it so fascinating for you and what was the perspective of your children too? Conley Being in Beijing is like being in the 19th century and the 21st century, sort of all at once. You can step back in time and you can also see some of the fastest urban growth on the planet, all in the same hour. The cultural dialects, the food, and the chaos on the streets, that is fascinating. It is also overwhelming, so for us it was sort of a lesson in how to pace ourselves and how to take it all in on our own time. Lamothe One of the things that I think we all know about China is the issue of the pollution, what was that like? How did China's health risks effect your transition

and your experience when you first got there?Conely I write about the pollution early in the book and I really never stopped writing about it. I call it a noxious white fog and for any of us who have lived on the East Coast or spent any time at the ocean, when that fog rolls in, it can stay for days and that is what happens in Beijing, the mountains ring the city, and the prevailing winds work to keep the pollution right over head, I called it sort of like a lid, a lid on a big bowl of the city and you would get the splitting headache, the cough and you would wonder how long you could all live there, and then the sky would clear and blue sky would prevail and you think, this is the greatest place in the world. So, it was always that dialect between wild amounts of pollution and then extraordinary beauty.Lamothe You are a writer by training and profession, among other things in the humanities, and so it always your intention to write a book about your experience in China, and then something happened to make this even more interesting, a more challenging experience in China? Tell us a little bit about your cancer diagnosis there?Conely You are right, I had every intention of writing a kind of mothering handbook of successes and disasters in Beijing, and I had started that book. I was halfway through that book which was kind of a reflection on motherhood in Beijing and was full of humor and sort of all that wonderful, poignant stuff that young kids say when they are learning about a new country and then that book was over the day that I found my breast lumps, and I did find them myself on a sunny Tuesday morning in Beijing. For all of us who have had cancer, it strikes when we are least expecting it, no one expects it and then things moved quickly after that.5:48 into mp3 file <http://yalecancercenter.org/podcast/mar1311-cancer-answers-conley.mp3>Lamothe What happened?Conely I had a feeling that these were more than simple cysts, and there was what is now a seemingly fascinating cultural collision, but at that time it was really frustrating, I could not get the Chinese doctors to pay much attention, so there was a sense that I knew something was going on, but I have to say that cancer did not sound the alarms there the way it does here.Lamothe And why do you think?Conley I wrote about this a lot in a book, and I think that first of all breast cancer just isn't as prevalent there by a long shot and there was this sense from my very old school Chinese surgeon that we did not need to go and explore those lumps because I would not want to have the scar. So, I had to contend with this notion that I could care less about the scar and I have to say, if there was a moment that is sort of the telltale moment in the book, it is where I called my American doctor and I say, well the Chinese doctors say it is no problem, I will wait six months, and she said no you will go back tomorrow.Lamothe Tell us how you prepared for that? Because you came back to Boston for that consult and treatment?Conley That was a phone conversation, and that was the beauty of having a doctor willing to take my call from China and be there for me and she is one of the heroes of the book and of my story because she said no, you will go back, so I marched right back and I said you know we actually have to get this lump out, and although the doctors in China were very dismissive, once we found out that we had a malignancy on our hands, we had our first surgery in China, then they wanted to go into warp speed, so that was kind of

fascinating, and we wanted to hold back and we stopped and we said you know what, we are going to gather our thoughts here and then we did go back to Boston. Lamothe Tell me what happened when you got back to Boston? What course of action did you take? How did you prepare for this journey that you had just begun? Conley Like so many survivors, cancer effects the whole family constellation, as I call it in the book, so we had to think about when do we pull the kids from school, where do we live, we knew we needed to have a surgery in Boston, but we didn't know what would happen after that, but we were very lucky, we made a big outreach to our wide community of friends and family and that was one of the most affirming moments in the whole journey. We sent out a kind of an e-mail missive, that said help. We do not know what we're doing here, we do not know which doctor to see, and I can't tell you how many responses we got from that, people from all over the world. I found out that I had a malignancy on a Friday in Beijing, and by Tuesday morning I was being seen at Massachusetts General Hospital in Boston. Lamothe Wow.8:51 into mp3 file <http://yalecancercenter.org/podcast/mar1311-cancer-answers-conley.mp3> Conley Yeah. Lamothe Tell us a little bit about the treatment, and how long it lasted, because then something interesting happened after your treatment ended. Conley I had a wonderful surgeon at Massachusetts General and like all of us who have had cancer, my story took some unexpected turns, we thought we were dealing with a very straight forward cancer, but after mastectomy we realized there was more going on, and I do say in the book that my cancer was oddly convenient because I received treatment for about four-five months, but I was done with radiation by the time Beijing schools started again. So, we made a big decision to move back to Beijing after that cancer. Lamothe Tell us about that decision, I would think that Beijing could be put on hold for a while, maybe indefinitely, and that the States was the place for you to be, you would go through your treatment, and then after treatment you'd want to hang out for a while and make sure that things were good, and that you had a firm footing under you, but you jumped right back into Beijing. Conley It was a tough decision. It came down to the fact that we wanted to keep our family together and my husband had a job there. That is where his job was, the kids had found a wonderful school. I had just enough friends to think I could make it because it is all about your support system at that point. We thought hard about staying. I decided not to do chemo in the end. I did radiation and I do a hormonal suppression. I was on the cut off line for chemo and I was fortunate to have an oncotype test that helped me make that decision. Going back for me was less worry about what kind of treatment I was getting, and I did go back to Beijing with a duffel bag of pharmaceuticals and a letter from my doctor and it was actually fine to travel like that. But one of the things that the book looks at and something that I really had to reckon with was the fall-out after you are done with treatment and you land anywhere, in my case, I landed in a foreign country and I liken cancer to a foreign territory. Another language you have to speak, and that was almost the hardest part. I thought in the book, I should be doing cartwheels, why I do feel so down? Lamothe Exactly, I think that our listeners who had a cancer experience would agree that when you go

through cancer you are very focused on your treatment, you are very focused on doing everything you can, keeping the family together, getting the support you need, doing what you are supposed to do, and then it ends, you are cancer free and everyone hopes you get back to who you were before, but you can never be that person because that person never had cancer and you are a person who will always have cancer. Conley Well put. And I find that often it is only other survivors that understand that and speak that language. For me it was fascinating because a lot of my new friends in China were Chinese and they were expatriates from European countries. There was a lot of cultural nuance, who can I talk to about these life changes I have gone through, who would understand, and I think all of us who have gone through cancer need to find those people. I wrote a little essay actually on my website. It is an ancillary piece where I say you might want to have a code word for your best friend and that is all you need to say and they know you are going to need to talk cancer. I was lucky I had that person, she was not in China, but we talked a lot on the phone and a lot of Skyping. Lamothe And she had had a cancer experience? Conley She had. Lamothe There is a broader network of support that is so critical both during treatment and after treatment and some people would argue that for them it is more important after treatment because of the trauma or dealing with the trauma after the trauma itself. But very close to you are these three people, your husband and your two sons. You can have a conversation at a level with your husband that you cannot have with your kids. Say a little bit about how the two of you prepared to talk to your children about your cancer diagnosis, because you have said it was a week or several days before you broke the news to them and they were part of your treatment and all the time following your treatment. I am curious to know how you conversed with them, how you consoled them as their mother while being a cancer patient and a spouse to someone who is terribly worried about you. Conley I had this gift, I met this doctor about a week into the journey. She was in Boston when I flew back and she said, you seem exhausted. I said, yeah, and she said it must be hard to be dealing with cancer and not telling your kids about cancer, it is a really hard thing you are trying to do and I said, but I am trying to protect my kids and she said, I believe that everyone gets one lie to tell to their kids about cancer. You have used your lie, so why not go back to China and try telling them the truth? And I thought, the truth? But the world is going to stop if I tell my kids I have cancer because then the cancer will be real. But I got off that airplane and my husband met me at the airport and he thought we could sort of take a long trip leisurely back to the house and I said no, we have got to go back right now, I need to talk to the kids. Lamothe We are going to a break right now for a medical minute, and when we come back let's talk about that conversation. Please stay tuned to learn more about Susan Conley's experience with breast cancer. Lamothe Welcome back to Yale Cancer Center Answers. This is Peter Lamothe and I am joined today by my guest Susan Conley and we are discussing her diagnosis with breast cancer and her new book. When we went to break, we were talking about how you de-

cided to tell your children the truth when you got back to China, tell us about that. Conley The wonderful doctor that gave me my one lie chit also said, hey if you tell them the truth all they really want to know is that you are going to live and if you can convince them of that they are going to go back to being self involved four and six year olds, and that is basically what happened. My six year old looked me in the eye and said, "Are you going to die?" I said no, and I did not feel like that was a lie. I felt like that was an affirmation and we took it from there and we subscribed to this sort of, we give them as much information as they ask for and we keep it on their level and the conversation is ongoing. But it was so liberating to tell them the truth.Lamothe That is terrific. Let us shift gears a little bit now, I understand that a chapter from your book was excerpted into the New York Times magazine, and I want to hear about your skill of negotiating and bartering for the statue of Buddha in a flea market in China.Conley I woke up one day in China and I was still having that sort of fall-out feeling from the cancer treatments and wondering when I was going to go back to being that person I used to be, of course now I realize that that is impossible, but I decided, hey, we could use a little help here. China was undergoing a Buddhism boom and the government had sort of sanctioned religion again, particularly Buddhism. So everywhere you looked there were Buddha heads and Buddha iconography and we headed out to this flea market with the intention of buying some kind of talisman, something to help ward off the cancer. I say in the book that this is what we are doing now, we are knocking on wood, and we are eating our fruits and vegetables, and we found this great old Buddha head that we tried to bargain for, but as the story goes in the excerpt, we did not do such a great job. We paid a lot more money for something that was not very old. I end the piece by saying, but he is my Buddha now and I love him.Lamothe It was made in China?Conley Yeah, it was made in China and I still love him and he is in our house and he looks down on us in our living room in Portland, Maine now, and he will always be with us. 18:56 into mp3 file <http://yalecancercenter.org/podcast/mar1311-cancer-answers-conley.mp3> Lamothe So, you are back in Portland, Maine now? How long ago did you move back? What was the decision like to return?Conley We have been back for a year from Beijing. I finished the book in China and then it was time to publish the book and my husband had reached a natural place in his job where he was able to hand off the reins to a Chinese national and it felt like time to go home and see what being in my old house would feel like post cancer. I actually close the book by saying, very honestly, that I had this secret hope that somehow going back I would be able to erase some of the cancer, like stepping through a portal, and of course that was not the case and that did not happen, but I needed that grounding. I needed to have that normalcy again. China is very much in our life still, my husband goes there often, and will go for the month of June. We are trying to hold on to the Mandarin, but it feels great to come back.Lamothe How did you talk to people? What kind of the questions did they ask you when you came back, about the cancer, about its impact on your family, and your choice to return? Some people may associate that with giving up, or quitting Beijing, which was

the cancer reminder, behind you, and starting fresh someplace else, but it did not sound like that to me. It sounds like your life is always about moving forward with your family. Conley Yeah, nicely put. There was nothing about giving up, although I do think there are a lot of folks that did want to translate it into, you are home, let's stop all that crazy China stuff, but for me China was so fascinating and so rich, and we traveled so much there that I actually liken it in the book to this great cancer distraction. I feel so fortunate to have been able to go on one of the greatest road trips of my life post-cancer because once I got back up on my feet post-cancer, I looked around and there I was in China, what a great thing. I said in a reading the other day, speaking for myself, I needed my life to be different after cancer and I did not know how, and I think everyone has to articulate that in their own way, but for me being in China allowed that difference to take hold. I was not the same person, nor did my life look the same. I began really embracing that and we were traveling all over China in trains, planes, and automobiles, and I always felt like I was actually putting cancer further and further behind me there and coming back has been a wonderful thing, but that does not mean I do not miss parts of China very much. Lamothe I think survivors are certainly entitled and many do take from their cancer experience what they want to carry with them and leave what they want to behind them, what they no longer wish to be a part of them. What I am curious to know from you, we have talked about why you started the book, how cancer came into it, but now people are reading your book, what do you hope they learn about China, about cancer, and about you? Conley The trifecta. I will start with cancer and me, and I think that they are interwoven. In the book, what I liken China too, again, is that foreign country, that foreign land, and the metaphor that I was holding onto throughout the whole book was, does cancer have to be an isolating foreign country, does it have to take you so far away from home, literally and metaphorically, and I am able to 23:10 into mp3 file <http://yalecancercenter.org/podcast/mar1311-cancer-answers-conley.mp3> solve that in the end of the book with a resounding no. You do not have to retreat, you do not have to shut-down, you do not have to stay in that foreign place where you do not speak the language, you can come back around the other side, you can come out. That is how I was able to translate cancer in the book. For China, it is the people and there are some starring characters in the book that are beloved friends of ours who we will never forget, and the big heartedness of those friends and the way that they embraced us was just something to behold and we are so grateful for that. I think that often gets lost in all of this stereotyping and the misconceptions here in the States. I got asked that question a whole lot, about the entire country's generosity, and I would say, if you only knew. Lamothe It sounds like generosity does not know borders or cultures; it is just a human condition. Conley Very much so. Lamothe What do we learn about you, what did you learn about yourself, and what do you hope that we as readers of your book take away, whether we're breast cancer survivors, cancer survivors, or people who are just moved by such a remarkable story? Conley I was driving in the car last week with my 10-year-old and out of the blue he asked me one of those

fourth grade questions, he said mom, what is the moral of your story? And I froze for a minute and said what I think is the answer to your question as well, for me, the moral was about being open and taking a risk and keeping the family together. I am so changed by cancer and not necessarily for the worse. I think my book is about hope and about family.

Lamothe Earlier, when we were talking, you said that you began to speak publicly about the book at public events and you get questions about China, but what really moves you were the questions about cancer. Could you say a little bit about the questions you have got? What surprised you and how you answered them?

Conley Yesterday I was asked by a survivor something similar to what you have gotten at a bit today, but she asked it very straight forwardly, why on earth did you go back to China after your cancer and she gave language to some of thoughts that I had not even been able to articulate which was, that was a turning point for our family, that we were willing to kind of embrace the unknown and I think we are much more resilient than we thought we were, and I will speak for myself and say that like many cancer survivors I know and love, because I have met many and I have been fortunate to be in some incredible survivor groups, we are all stronger than we might have thought we were.

Lamothe Knowing that, and feeling that, what are you doing? What do you hope that you will do going forward for the cancer community, people who are affected by this disease, either through your writing, though a project that you are thinking of, or some other way. How are you going to give back in addition to what you have already done so well?

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Conley Part of this book tour has ended up being this fascinating journey to cancer centers. I have a pretty full schedule ahead of talks at cancer centers and the enthusiastic response to the book and to me speaking with survivors has been really heartening, and I had started a creative writing center in Portland, Maine about five year ago. It is called The Telling Room and it is this thriving place for high school aged kids and middle schools kids in the whole Portland area. I co-founded it, and I teach at it, and I can very much see a kind of health cancer writing piece being implemented there. So, that is on the back burner right now.

Lamothe That is terrific. So, as we approach the end of our conversation, which has just been terrific, I want to say one thing which is, you obviously have to refer to the book, but the book is about you and so it is a terrific book and you are terrific, your experience and your willingness to share it with so many people that you may never come to know but who will be positively impacted by it. I think people who are listening want to know, and you may get this question as you continue to speak across the country and maybe around the world, but how you are doing, how is your health, and how are you taking care of yourself?

Conley I always thank people when they ask me that, and I am sure you do too. I just think it is sometimes the elephant in the room and it is just so nice for people to ask and then you can say, great, thanks, because that is my story right now. I am almost three years out and I am feeling strong, feeling good. I get a lot more sleep now and I do watch the nutrition piece. I am very aware now of getting run down, but I am feeling very optimistic and hopeful.

Susan Conley is a cancer

survivor and the author of *The Foremost Good Fortune*. If you have questions or would like to share your comments, visit yalecancercenter.org, where you can also subscribe to our podcast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.